

Virginia Genetics Advisory Committee INFRASTRUCTURE

I. Mission

To coordinate access to clinical genetics services across the Commonwealth, assuring the provision of genetic awareness, and quality services and education for consumers and providers taking into consideration issues of confidentiality, privacy, and consent.

II. Membership

A. Current Members

1. Description: Those individuals or their designee/replacement who were present at the 10/29/02 Strategic Planning Meeting.
2. Representation: Individuals who represent the following agencies and organizations.
 - a. Division of Consolidated Laboratory Services
 - b. Eastern Virginia Medical School / Children's Hospital of The King's Daughters (Genetics and Metabolic Treatment Centers)
 - c. March of Dimes, Virginia Chapter
 - d. University of Virginia (Genetics and Metabolic Treatment Centers)
 - e. Virginia Commonwealth University (Genetics and Metabolic Treatment Centers)
 - f. Virginia Department of Education (Student and School Support: Health and Medical)
 - g. Virginia Department of Health
 - h. Virginia Department of Behavioral Health and Developmental Services: Infant & Toddler Connection of Virginia (Part-C Early Intervention)
 - i. Virginia Early Hearing Detection and Intervention Program Advisory Committee

3. New Members

- a. Description: Work groups will add members as appropriate and invite to VaGAC meeting as appropriate. Representatives from the following agencies, organizations, and businesses are suggested.
- b. Representation: Individuals who represent the following agencies and organizations.
 - (1) Insurance
 - (2) Parents\
 - (3) Commercial laboratories
 - (4) Internal medicine
 - (5) Family medicine
 - (6) Legal representation
 - (7) Local Health District Director
 - (8) Ethicists
 - (9) Virginia Hospital and Healthcare Association

III. Meetings

A. VaGAC Meetings

1. Purpose
 - a. Review and act on work of subcommittees and workgroups.

- b. Identify and focus attention on what issues are on the horizon to be addressed within mission/purpose.
 - c. Set priorities.
 - d. Make decisions when appropriate.
- 2. Schedule
 - a. Regular Meetings: Twice a Year
 - (1) April or May
 - (2) September or October
 - b. Emergency Meetings: As called by the VaGAC Steering Committee.
- 3. Subcommittee and Work Groups Meetings
 - a. Purpose
 - (1) Seen as a means to an end, not the end.
 - (2) Their work is to be reviewed by the total Committee.
 - (3) Schedule: Will meet separately to fulfill their work in preparation for sharing at the Committee meetings.

IV. Decision Making and Quorum

- A. Decision Making
 - 1. The VaGAC will use modified consensus as their tool for decision-making.
 - 2. Voting may be used when speed is of the essence and differences cannot be mitigated within a limited time frame
- B. Quorum: One over ½ of the VaGAC members present at an announced scheduled meeting will constitute a quorum.

V. Communications Tools

- A. VaGAC meeting minutes will be sent electronically to all members.
- B. VaGAC meeting minutes, are available at the following Web sites:
 - 1. Virginia Genetics Advisory Committee
<http://www.vahealth.org/PSGS/vgac.asp>
 - 2. VDH Meetings Calendar
<http://www.vdh.state.va.us/minutes/minutes.asp>
 - 3. Virginia Regulatory Town Hall
<http://www.townhall.virginia.gov/>

VI. VaGAC Steering Committee

- A. Members
 - 1. Joann Bodurtha, Chair
 - 2. Nancy Ford, Staff
 - 3. Willie Andrews
 - 4. Bill Wilson
 - 5. Ginny Proud
- B. Functions
 - 1. Set meetings
 - 2. Form the agenda for meetings
 - 3. Decide when to call emergency meetings
 - 4. Respond to legislative inquires

5. Respond to press inquires
- C. Meetings / Chair
 1. Steering committee will meet by conference call as needed
 2. Chair represents the voice of the Committee

VII. VaGAC Subcommittees and Work Groups

A. Newborn Screening Subcommittee

1. Goal:
2. Members
 - a. Willie Andrews, Chair
 - b. Stephen Braddock
 - c. Laura Duncan
 - d. Sarah Elsea
 - e. Audrey Greene, Staff
 - f. Anil Kuma
 - g. Kathleen Link
 - h. Sara Long
 - i. Jennifer Macdonald, Staff
 - j. Arti Pandya
 - k. Ginny Proud
 - l. Jim Pearson
 - m. Charlie Stevenson
 - n. Susan Ward
 - o. Bill Wilson
 - p. Sharon Williams, Staff
 - q. Other if indicated

B. Birth Defects Prevention Subcommittee

(4/1/08: Changed name from Community Partnerships/Parent Involvement Subcommittee)

1. Goal: To develop a process whereby parents review policies, materials, publications and other such matters.
2. Members
 - a. Tiara Green, Chair and Staff
 - b. Joann Bodurtha
 - c. Sharon Williams
 - d. Jana Monaco
 - e. Vicky Hardy-Murrell
 - f. Valerie Luther
 - g. Alice Schroeder
 - h. Cliff Schroeder
 - i. Heather Trammell
 - j. Paula Miller
3. Future Members
 - a. Virginia Council on Folic Acid
 - b. VDH Fetal Alcohol Spectrum Disorders Task Force

C. VDH Contractors Ad Hoc Work Group

(4/28/2009: This ad hoc work group replaced the VaGAC VDH Contractors Subcommittee.)

1. Purpose: A forum for discussion and resolution of issues concerning contracts.
2. Schedule of Meetings: Work group will be convened by the VDH Genetics and Newborn Screening Director on an "as needed basis."
3. Members: Individuals who represent the following contracts with VDH: EVMS, UVA, and VCU.
 - a. Nancy Ford, Chair and Staff
 - b. Ginny Proud
 - c. Joann Bodurtha
 - d. Bill Wilson
 - e. Laura Duncan